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ABSTRACT

To determine the effects of potentially difficult behaviors (tendency to talk too much, difficulty in processing what others are saying, inattention to details, inappropriate responses to the feelings and emotions of others, and emphasis on sameness and ritualistic behaviors) on community based programs, the records of five autistic youths and adults were examined. Interviews with group home house managers and guidance counselors were also conducted. Results showed that all five problem behaviors were observed in at least four of the five Ss. However, only two were considered especially problematic: the tendency to talk too much and the emphasis on sameness and ritualistic behaviors. Two other problems were identified: difficulties in money management and self stimulation. (Author/CL)

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Social and Interpersonal Problems of Autistic Adolescents and Adults

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Social and Interpersonal Problems of Autistic Adolescents and Adults

The field of pediatric psychology includes the "interests and concerns of psychologists who work in interdisciplinary settings such as hospitals and developmental clinics." Historically, work in the area of pediatric psychology has been about equally divided between these two settings. Hospital-related practice has dealt primarily with psychological and behavioral aspects of medical problems such as those described in the other papers of this session. The other main area of interest, stimulated primarily by those working in interdisciplinary developmental clinics, has involved work with handicapping conditions. This presentation will emphasize an applied approach to the psychological treatment of problems related to one such handicapping condition; namely autism.

Although there is some disagreement among investigators on the precise definition of autism, virtually all concur that one of the most important components includes impaired social relationships (Kanner, 1946; Ornitz & Ritvo, 1968; Rutter, 1978). These relationships, studied most frequently in infants and preschoolers, are usually marked by a lack of early attachment, bonding, eye-to-eye gaze, and responsiveness to people. Though studied less frequently and changed in form, social problems of adolescent and adult autistic people are no less severe or handicapping. Problems noted in this group have included lack of cooperative play, lack of empathy, failure to make friends, and difficulty in adjusting to school or residential programs (Everard, 1976; Kanner, Rodriguez, & Ashenden, 1972).

Prior to the recent emphasis on normalization, mainstreaming, and the development of community-based alternatives to institutionalization (Wolfensberger, 1972), many social problems of adolescent and adult autistic people were not of primary concern because approximately 50-75% of these people resided in institutions (Lotter, 1978). However, the recent emphasis on integrating handicapped people into community-based programs requires that greater attention be paid to those social problems which are likely to interfere with such placements. The purpose of this paper is to describe some problems of social and interpersonal skills of autistic adolescents and adults living in community-based facilities and attending community-based programs such as group homes and public schools. The focus will be on higher functioning autistic persons (IQ greater than 80). Although this represents a minority of autistic persons (most estimates suggest that 70% of all autistic persons have IQs less than 70) (Schopler, Mesibov, DeVellis, & Short, in press), it represents the group most likely to be integrated into programs serving persons with other kinds of developmental disabilities such as mental retardation.

In reviewing the literature on autistic adolescents and adults to try to determine what kinds of difficulties they might have in community-based programs, one finds that the literature is quite meager. The few papers available (Everard, 1976; Kanner et al., 1972) emphasize 5 areas of potential difficulty: (1) tendency to talk too much; (2) difficulty in processing what others are saying; (3) inattention to details; (4) inappropriate responses to the feelings and emotions of others; and (5) emphasis on sameness and ritualistic behaviors.

To determine the affect of the 5 kinds of potentially difficult behaviors on community-based programs, 5 clients, ranging in age fr 16-30 and with IQs from 80-120, were selected for study. All were in programs that were not designed specifically for autistic persons: 4 were in group homes for mentally retarded adults and 1 was in a public school program for mentally retarded high schoolers.

The procedure was to interview the person primarily responsible for the autistic person in the setting; the housemanager for the clients in the group home and the guidance counselor for the client in the public school program. School and home records were examined as a cross-check on the reliability of the interviews. In general, what was said in the interviews closely matched what was written in the records.

The interviews and records were first analyzed to determine which of the five areas of potential difficulty are, in fact, problematic in these community-based settings. The tendency to talk too much is definitely a major concern. Talking to one's self, bringing up topics unrelated to the general conversation, and dwelling on seemingly nonsensical and insignificant details were mentioned frequently as problems. One girl talks incessantly about boys and rock stars no matter what the others are saying. She also talks about specific concerns related to current events such as the kidnapping of Patty Hearst or the lack of water during a water shortage. Another man initiates much foolish conversation. For example, after being introduced he often says, "What TV station do you like? Do you get Channel 37" He also frequently plays games with words that he hears on TV commercials. Irrelevant and often inappropriate talking is considered a problem for 4 of the 5 clients discussed.

Another kind of excessive talking, continuing to pursue specific topics for long periods of time and obsessing over specific details, is also perceived as a problem in 4 of the 5 cases. Although the respondents were concerned about both types of excessive talking, it is this latter kind that seems more difficult for them to cope with. The consistent, repetitious questioning is something that seems to wear people down after awhile.

The second area, difficulty in processing what other people are saying, was noted in all five of the clients. This difficulty often makes it appear as if autistic people do not hear what is being said to them. It can also make it difficult for some autistic people to keep up with the flow of a conversation. Although this problem was noted and acknowledged as annoying, often requiring repetitions of instructions, this was not seen as a major concern of the housemanagers or teacher.

The third area of difficulty, inattention to details, was also cited in all of the cases, but not perceived as a major problem. Indications of this were short attention spans, making it difficult for the autistic clients to maintain their interest for long periods of time; and difficulty following conversations. Though noted, these behaviors were not perceived as interfering significantly with the group home or public school programs.

The fourth area, inappropriateness of autistic people's responses to specific feelings and emotions of others, was hard for respondents to separate from the inappropriate social responses of these clients in general. Although social problems are of concern, these are not more severe when relating to others' emotions than for any other aspect of social interactions.

Finally, the ritualistic emphasis on sameness, a characteristic of autism throughout the lifespan (Kanner et al., 1972), was noted in all five of the cases and perceived as a very important and difficult problem. In general, these settings do not have the structure and day-to-day continuity that many autistic people need. In addition, staff turnover in these programs is high, often precipitating additional crises for the autistic clients. Although all 5 clients exhibited greater flexibility with longer participation in their programs, housemanagers and teachers still consider a major difficulty as being the mediation of clients' high need for structure with the usual day-to-day changes that accompany most community-based programs.

In summary, of the five areas of potential difficulty for autistic adolescents and adults cited in the literature, all were observed in at least 4 of the 5 clients under consideration. However, only two of them were considered to be especially problematic in the group home and public school settings; including the tendency to talk too much, especially when dwelling on specific concerns, and the emphasis on sameness and ritualistic behaviors.

In addition to the above-mentioned concerns, there was one other area of major difficulty in these two settings. This involves the tendency for the autistic people to become very upset. Although none of these clients become especially aggressive when upset, their tendency to become agitated, irritable and to withdraw at these times is very problematic for those dealing with them. This was described as a major problem in all of the 5 cases that were reviewed.

In addition to the already described concerns, there were several other problem areas mentioned in a majority of the cases. Although these

were not perceived as major problems, they were nonetheless concerns of those working with these autistic people. First, there is considerable difficulty in handling and managing money. Interestingly enough, the difficulties equally represent the two extremes. Two of the group home residents are perceived as extremely loose and free with their money, being unable to budget or manage it in any meaningful way. The other two are perceived as extremely rigid, refusing to spend any of the money they earn. Apparently, money management is a judgmental issue with which many autistic people need some extra assistance.

Second, there is evidence of self-stimulatory behaviors on the part of these clients. One woman tends to slap herself when upset, one man has some stereotyped postures, and the others show similar behaviors such as rocking when upset or before going to sleep. These behaviors are idiosyncratic to each resident and are performed consistently at predictable times. Although these behaviors appear unusual and inappropriate to the caretakers, they do not seem to be bothered by them to a great extent.

In summary, the major problems confronting those working with autistic people in community-based settings, that are not specifically designed for this population, include incessant talking, ritualistic behaviors, and a tendency to become very agitated and upset. Other problems, though perceived as much less severe, include difficulty in processing what others are saying, inattention to details, inappropriate responses to feelings and emotions, poor money management, and self-stimulatory behaviors.

Given these descriptions of the problems and difficulties, it is encouraging that peer relationships are not of major concern. Although

none of the informants described the peer relationships of their autistic clients as exemplary, this was, nevertheless, not perceived as a major impediment to successful adaptation. Apparently the peer relationships of the autistic people are at least adequate for these group home and public school settings.

Given these difficulties in integrating higher functioning autistic persons into community-based programs designed for mentally retarded persons, the question becomes whether or not this is a viable treatment strategy. The case studies described in this paper suggest that it is, although all of the teachers and housemanagers stated that the autistic people require a great deal more time and effort than mentally retarded people who don't have autism. Knowing this, one strategy would be to provide extra support and assistance to those programs willing to serve autistic persons. This could involve extra money, extra staff, and extra consultation. In addition, state and federal programs funding services for mentally retarded persons could give priority to those programs willing to serve some higher functioning autistic people as well.

In addition to administrative and personnel assistance to those programs willing to serve autistic people, another way of facilitating the integration of autistic people into programs for mentally retarded persons would be for us to better understand why autistic people are perceived as more difficult to serve. In the settings described here, it would appear that this should not be the case. The autistic clients in these programs are much higher functioning in terms of their self-help and their cognitive skills than the mentally retarded clients. None evidenced any of the severe behavior disorders that often accompany autism. Why, then, are they perceived as so difficult to manage?

. Several possibilities suggest themselves for why these clients are perceived as more difficult to serve. First, the fact that they appear more normal than mentally retarded clients might represent a problem. Looking less handicapped and having more skills might lead others to expect more from autistic people than their capabilities warrant. When autistic people are not able to meet some of these demands, this could lead to greater disillusionment and confusion on the part of those working with them. These uncomfortable psychological feelings might be what the teachers and housemanagers are responding to when they say these clients are more difficult to manage.

The second possibility is that the periods of severe agitation make these clients more difficult to handle. Perhaps this is because it makes teachers and housemanagers feel inadequate in not being able to deal with these. Although the clients described in this paper are rarely aggressive toward others, these periods of agitation might frighten teachers and housemanagers into thinking that they could become aggressive when they are so out of control.

Third, it could be that the idiosyncratic behaviors of these autistic clients are just very irritating. Perhaps the constant talking and questioning, though humorous at times, can wear down the most patient of housemanagers and teachers. Moreover, having to always maintain a very rigid routine in these community-based programs might put extra pressure and burdens upon the housemanagers and teachers.

Finally, a possibility is that the autistic clients are constantly forcing teachers and housemanagers to schedule themselves around these clients. Their need for structure and propensity to become easily upset might require major adjustments in the daily schedule. Many of the

mentally retarded clients are more flexible and can more easily adjust to the routine of the house. Having to adjust the routine of the program to the clients might be more than many housemanagers and teachers are willing to do.

Clearly, more research is needed to pinpoint which of the above aspects of dealing with autistic people is most problematic, or to generate some new alternatives. This is a most important area of research if we are to be able to provide the support and assistance necessary to allow autistic clients to function comfortably outside of very costly, highly specialized programs. If we can better understand the reasons these autistic clients are perceived as so difficult to manage, we will be in a much better position to intervene when problems occur. This understanding will also give us a better knowledge of autism and of how the management of autism needs to differ from the management of mental retardation and other types of developmental disabilities.

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